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ABSTRACT

The Healthy Beginnings program is designed to help parents of prematurely born infants adjust to parenting challenges and opportunities of the first 2 years of the infant's life. The Healthy Beginnings Program provides parents of premature infants with support and guidance by offering: (1) monthly education and support meetings; (2) evaluations for the infant at the Meyer Center for Developmental Pediatrics at the Baylor College of Medicine on a regular basis; and (3) instruction in ways to improve parent-child interaction patterns. The discussion of the program elaborates on these program offerings, and also covers family life after infants leave the neonatal intensive care nursery, parental stress 2.5 months after the birth, and family life after a year of program participation. Typically, parents of premature infants magnify and attempt to fulfill irrational beliefs involving the words "should," "ougnt," or "must" which are incompatible with reality and cause an inordinate amount of tension and dissatisfaction. Program staff use group and individual meetings to help parents identify and overcome their irrational beliefs. The program places a strong emphasis on the deliberate use of logic, the development of flexible and appropriate expectations, and the introduction of specific behavior patterns. (RH)

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When Will Life Be Normal?

The Healthy Beginnings Program for Parents of Premature Infants

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When Will Life Be Normal?

The Healthy Beginnings Program for Parents of Premature Infants

by **Elizabeth Sledden, Ph.D.**

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Foreword

Parents of prematurely born infants begin parenthood abruptly. They are quickly ushered in with little or no time for preparation. Often the premature infant requires prolonged hospitalization and experiences numerous life-threatening medical complications. During this period, parents ride an emotional roller coaster, their peaks and valleys matching their infant's changing medical status until survival is certain. Today, with modern neonatal intensive care services, most prematurely born infants do survive to be discharged home to their families.

As chances for survival have increased dramatically, it has become evident that premature infants are at risk for developmental problems. In addition, behavioral differences are often present. These developmental and behavioral characteristics together with the emotional intensity felt during those first few months of life make parenting the premature infant both exceptionally challenging and rewarding.

Healthy Beginnings—Parenting the Premature Infant is a project established at the Meyer Center for Developmental Pediatrics, Texas Children's Hospital and Baylor College of Medicine in Houston. This pamphlet describes common parenting issues which mothers and fathers of premature infants often face and offers processes for addressing these issues as provided through the Healthy Beginnings project which has support from grants by the Ima Hogg Foundation.

This publication is dedicated to Murdina M. Desmond, M.D., Professor Emeritus of Pediatrics, Baylor College of Medicine, and for many years Director of the Meyer Center. Dr. Desmond began the first follow-up services for premature infants in Houston and established the concept that high quality neonatal intensive care requires equally high quality follow-up services to assure the best possible outcome for prematurely born infants and their families. I believe today's Healthy Beginnings continues those services for which Dr. Desmond has so fervently advocated.

W. Daniel Williamson, M.D.
Director, Meyer Center for
Developmental Pediatrics

When Will Life Be Normal?

American-Statesman photo by Lynne Dobson

The Healthy Beginnings Program
for Parents of Premature Infants

Charlie entered this world two and a half months early. His parents, Jan and Matt, were very surprised, as this, their first pregnancy, seemed to go "by the book." Charlie's arrival was greeted by a crowd of medical staff and lots of unfamiliar equipment. There was such urgency to his birth that Jan didn't even get to see him. He was quickly weighed and cleaned, a tube was put down his throat to help him breathe, and he was taken to the Neonatal Intensive Care Nursery (NICU). "Will he survive? Is he in pain? What did we do wrong?" was all Jan could think about as she lay in recovery and then in her hospital room. Matt was torn with doubts, not knowing how to comfort Jan while he tried to cover up his own anxiety and anger at not being able to be with his new son. When they went to the NICU, Charlie's parents were bewildered by the number of machines that kept him warm, breathing, fed, and monitored. The noise in the room was deafening. And no one seemed to panic when the lights flashed and the buzzers went off! Charlie was so small and fragile-looking! He only weighed one-and-a-half pounds. The nurses didn't seem to notice that fact when they moved him around in his isolette. Matt and Jan were almost unaware of the other parents in the NICU and even though they wanted to cry out for reassurance, they stood by and numbly watched all of the goings-on, not even knowing what questions to ask.

As the early hours stretched into his first few days, Charlie began to show signs of being a fighter. Over time, Jan and Matt grew more confident and began to watch, talk to, and even hold Charlie. They could sense his strong spirit and felt closer to him all the time. The NICU became a roller coaster of experiences. It was filled with sudden and scary highs, twists, lows, and the even more terrifying drops in Charlie's condition. The flurry of calls, cards, and visits from family and friends began to subside as the weeks slowly passed and Charlie grew stronger. Jan and Matt relied on their parents and a few close friends for comfort. Most people, especially her friends who had already had babies or were pregnant themselves, were afraid to ask about Charlie for fear of upsetting Jan or hearing bad news. Co-workers didn't say much when Matt proudly showed pictures of Charlie in his isolette with all of the tubes and wires. They just smiled quietly and made vague promises of wanting to "help." Unfortunately, neither Matt nor Jan had any idea of what to do or what would make their lives more comfortable. After each visit they went home only part of a family. This wasn't the joyous "parenting experience" they had read about or seen on TV and in the movies. They didn't even have a chance to take childbirth classes or choose nursery furniture! Shopping for Charlie now only made them feel more empty.

The days turned into weeks, and Jan chose to go back to work to save her precious maternity leave for Charlie's homecoming. She hated to spend hours at work worrying about what was happening in the NICU. The months of phone calls and long lunch and evening visits took a toll on her strength and ability to be polite when people asked, "Why isn't Charlie home yet?" or "Why is he so small and sick?" Charlie was getting stronger and bigger every day and these people just didn't realize how far he'd come. Charlie's test results were improving and he was gaining weight. In fact, he was starting to look like a "normal" baby. He was even starting to smile at his parents while being fed. When would he come home? . . .

The day arrived, and they had only 24 hours notice. He was coming home after three months in the hospital! Little did Jan and Matt know what was involved in bringing Charlie home. They went to the hospital to learn just what to do for Charlie and when. The list of medications, eye drops, and vitamins; schedules for feedings; various types of formulas to consider; remedies for spitting up; significance of different types of bowel movements; requirements for room and body temperature; issues about weight gain; range-of-motion exercises; directions for the oxygen and apnea monitors; procedures for resetting the machines; and practicing emergency recussitation skills (CPR) were overwhelming. Jan simply couldn't remember it all. But Charlie was coming home at last.

The nurses brought Charlie out to the car in front of the hospital. His oxygen and monitor were loaded in, the medications and diapers were packed away, and at last Charlie was buckled into his infant seat in the back of the car. Matt couldn't believe it. This was the most important drive of his life. He had to get Charlie home safely! Jan sat next to the baby in the back seat and cried quiet tears of joy. The nurses said goodbye and shut the car door. With that one gesture, the new family was wished a good life with their boy, the one who was so small just three months ago. It was an eerie feeling. "Can we do everything for Charlie? He needed a whole hospital to take care of him just hours ago!" thought Jan to herself. "We have so many things to worry about! Will we do it all correctly? What if we can't tell what's wrong? Will I hear him wake up at night? What if the monitors stop working? When will life be normal?"

As medical technology continues to expand and specialize, smaller and smaller babies are able to survive. Infants with birthweights of one or two pounds now are able to survive with the help of new techniques and life-supporting machines. Consequently, the numbers of premature infants who go home from the hospital increase, as well as the numbers of small infants and young children with serious medical conditions or potential long-term disabilities. This pamphlet will describe common patterns found in families once the premature baby comes home. Obstacles to family growth and some ways to address these specific difficulties will also be presented. Families can better prepare for and meet the challenges when they are able to understand and identify their sources of stress. This knowledge can also help parents to help themselves while at the same time they encourage their child's development.

The Healthy Beginnings Program at the Meyer Center for Developmental Pediatrics at Baylor College of Medicine and Texas Children's Hospital is designed to help parents of prematurely born infants adjust to the unique parenting challenges and opportunities they will experience during the first two years of the infant's life. Prematurity is not selective; families come from all walks of life and have diverse lifestyles. The majority of the mothers are in their twenties or thirties, and generally this premature infant is the first child. In addition, some parents have premature twins or even triplets. The premature babies are very small, averaging two pounds at birth, although some weigh as little as one or one-and-a-half pounds. These infants tend to be born three months early, and some of the very small babies are born four months early. The Healthy Beginnings Program provides parents of these premature infants support, encouragement, and guidance by offering (1) monthly education and support meetings; (2) evaluations for the infant at the Meyer Center on a regular basis; and (3) instruction in ways to improve the parent-child interaction patterns.

Monthly parent support and education meetings are a forum in which general concerns can be raised, care-giving ideas can be shared, and new and anticipatory information can be provided from the medical, developmental, social, and emotional points of view. The basics of infant care, stimulation, and development are discussed in some form during each meeting. Many of the meetings focus on stress management and communication skills in an effort to moderate the tremendous pressures on the individual parents as well as their families and support systems.

Some parents have expanded upon the initial structure of this support group and contact each other between meetings. Many spontaneous calls have been received by the program's psychologist for advice and information about child rearing and development, for referral sources for outside therapy, and for brief marital/individual counseling sessions.

Premature infants who are enrolled in the Healthy Beginnings Program are given time to "catch-up" to their full-term peers by the use of the corrected age concept. The extent of each infant's prematurity is accounted for by calculating his or her age from the expected due date rather than the infant's actual date of birth. In essence, the length of prematurity is subtracted from the chronological age of the infant. For example, when an infant born two months early is chronologically four months old, the corresponding corrected age would be two months.

Each infant is seen at 4, 12, 18, and 24 months (corrected age) for multi-disciplinary evaluations at the Meyer Center. These evaluations allow the parents to raise developmental, medical, emotional, and management concerns during an intense, half-day visit. Unspoken concerns are often alleviated when parents are given the results of the evaluation, indicating present functioning levels in areas such as motor, social, verbal, and cognitive abilities. Referrals for outside therapy are made if needed. Time is spent observing the parent-infant play interaction during the clinic visits. Recommendations are made for specific toys or play activities as well as changes in the play pattern which will better accommodate the infant's temperament, tolerance, attention span, and developing abilities.

Most prematurely born children need a great deal more specialized and individual nurturance, guidance, and follow-up care than do full-term infants. Indeed, parenting a premature baby is not a "normal" experience. Research has taught us that "premies" tend to have more health complications than babies born at full term. Deficits in hearing and vision are common, with many prematures requiring eye surgery and/or corrective glasses or contact lenses. Variations in muscle tone are frequently seen and often require intervention with a physical or occupational therapist. Prematurely born infants are also susceptible to a number of respiratory and digestive disorders. Medical complications such as these have many implications for the parent of a premature. Feeding schedules are demanding, often with no more than two hours between feedings. Eating becomes more of a battle of

intake vs. spitting-out rather than a warm, bonding experience. Every ounce of weight gained is a hard-earned milestone and a signal of growth and progress. The number of doctors' appointments and daily medications is overwhelming and very time-consuming; they require an almost super-human level of organizational and memory abilities. A viral infection or common cold can quickly progress to pneumonia and hospitalization for these infants. Parents frequently keep the baby at home away from others for several months in order to avoid excessive exposure to these now-serious, "common" illnesses. This action leads to isolation and exhaustion for parents.

Behavioral differences are also found in the premature infant; the most important distinguishing characteristic may be the premature infant's difficulty controlling behavioral responses to the environment. These infants tend to be irritable, that is, quick to cry and tending to cry for long periods of time before calming down. It is also difficult for these infants to adapt to changes in temperature, foods, lighting, and such. Studies and direct observation also suggest that self-soothing or hand-to-mouth activities are difficult for these infants to achieve. Taken as a whole, the premature at home is easily disturbed, slow in returning to a calm state, and has difficulty indicating his or her needs. Even the basics of baby care cannot be taken for granted. These infants are typically too small for even "newborn" sized clothing or diapers. Many parents must purchase special diapers and doll clothing for their young premature infants. Even baby toys are generally too large or heavy for the typical premature to manipulate.

The Healthy Beginnings Program is designed to help parents deal with the shift from hospital care to life at home. A large portion of this adjustment involves coping with the daily impact of all the aforementioned medical and behavioral complications. Additional stress is added as most of these are first-time parents with little practical knowledge about baby care. No one can really tell the parents what to expect at home on a day-to-day basis and how to cope. The lack of predictions about the future only increases parental uncertainty. Some information on child development and many professionals seem to tell parents to treat this premie as a full-term child now that he or she is home. Yet, that view doesn't seem to coincide with all of the highly specialized treatment the baby has received so far. The Healthy Beginnings Program is a place where parents can turn for special guidance and support from experienced professionals and other parents who have "survived."

Parents are able to receive information and answers to common questions such as: What are the keys to raising a premature? Will developmental milestones really be the same for the prematurely born child as for a full-term child, but just acquired later? Will baby clothes from stores really fit some day? When will a cold be nothing more than just another runny nose? Will the hospital experience negatively impact a child's social adjustment? Should we avoid stressing and upsetting the child by enforcing behavioral limits? When will life be normal?

The new family had been home for two-and-a-half months now; routines were beginning to form, things should be settling down. But the worries were actually increasing! At five-and-a-half months (chronological age), Charlie was developing his own personality and that included position, temperature, and even food preferences. Jan worried continually about his weight gains; more formula ended up on her clothes than in his stomach. His immature esophagus which caused excessive spitting-up made feeding a long battle of wills and physical endurance. Charlie would take only a few ounces, refuse any more, and then demand to be fed just as everything was being cleaned up and put away! "When will his stomach accept four hours' worth of formula? Will finger feeding be *any* easier? Is Charlie getting enough nutrition? He's drooling so much and is so fussy, maybe he's teething and just doesn't want to eat?" The questions went on and on.

"I'm more tired at home than I ever was during all of those sleepless nights when Charlie was in the NICU," mused Jan. She hated to tell Matt just how exhausted she was every night when he came home. "After all, he works hard all day and doesn't need to worry about me, too. Taking care of Charlie is my 'job' now, I wanted this so much and all I can do is complain. I must be crazy! If only I could talk to another grown-up during the day . . . but I don't trust anyone else to stay with Charlie yet. It takes me two whole hours just to get us ready to go to doctor appointments, so I can't even dream of going out for 'fun!' Maybe if I had some help around the house, just to clean up the place. But the hospital bills are coming in and we can't even pay those! I used to be able to work a full-time job and clean and cook without Matt's help, why can't I do it now?"

Matt was having similar thoughts and he, too, hesitated to share his worries. Jan looked so frayed these days. He worried about money most of all. "We saved for this baby so Jan could stay home a while, but the NICU ate all of that up. I know a maid would help, but who could afford that! Besides, it only takes 15 minutes to do the dishes or run a vacuum. Why, I bet Jan could do that during one of his naps, if she only got more organized. She just doesn't use her time well. As soon as I walk in the door she acts as if the cavalry has arrived to save her from distress! I've had a rough day, can't I have a few minutes to regroup and relax before there's a fussy baby plopped in my lap?" Matt was also noticing Jan's constant state of frustration and lack of interest in adult topics—and in Matt's needs,

too. "When Charlie's asleep, he's all she can talk about, or complain about. I wonder if she wishes it were different. Jan doesn't want to be with me anymore and we used to be inseparable. I bet if I dragged her out to a movie, she'd fall asleep in the theater! Have I changed as much as she has? Is having a baby supposed to make you feel like this? Will our marriage ever get back to normal?"

Many adults become trapped in a circle of expectations, disappointments, and self-criticism which leads to further inflated expectations for future behaviors which result in even greater let-downs. This cycle of events is fueled by a long list of unspoken, and often unacknowledged, irrational beliefs. Usually these are unwritten ideals and expectations which are handed down through families. Almost all irrational beliefs involve the words "should," "ought," or "must." Irrational beliefs are by nature inconsistent and incompatible with reality. They eventually lead to rather intense feelings of anger, depression, anxiety, and low self-esteem. People whose daily actions are based on irrational beliefs quickly become inflexible and have tunnel vision, making any sort of compromise or rational problem-solving discussion difficult, if not impossible. Problem-solving is a typical daily activity of parents of premature infants, requiring that irrational beliefs be overcome so that parental efforts are efficient and successful. It is a difficult task.

Irrational beliefs can be easily experienced by most parents, yet are felt in much greater intensity and frequency by parents of prematures. In part, the amount of time the baby spends in the NICU and the typical, yet self-defeating, guilt many parents have about premature labor and delivery lead parents to have extraordinary high expectations about their own abilities and a sense of urgency of the infant's every need. The staff of the Healthy Beginnings Program has found that parents of premature infants magnify and attempt to fulfill the following irrational beliefs, without a great deal of success, and with an inordinate amount of unnecessary tension and dissatisfaction.

1. I *should* be able to detect and meet all of my child's needs.

2. I *should* be a competent parent at all times; being frustrated and complaining are not acceptable behaviors.

3. I *should* be in complete emotional and intellectual control at all times.

4. I *should* constantly work with my child at home to overcome the impact(s) of a premature birth.

5. I *should* enjoy caring for my child's needs and want to be with him/her as much as possible.

6. I *should* unquestioningly rely upon and allow medical personnel to direct my child's care: they are the authority on my child.

7. I *should* be able to follow through on all therapeutic recommendations to improve my child's progress.

8. My child's development *should* be similar to other children's and those in books on normal development.

9. My intimate and social relationships *should* be of lesser importance than being with my child.

10. Everyone (spouse, relatives, friends, co-workers, medical staff) *should* realize how hard it is to be a parent of a premature infant and they *should* show their respect and gratitude.

Through group and individual meetings, the staff of the Healthy Beginnings Program helps parents of prematurely born infants identify and then overcome their own unique irrational beliefs. The process of eliminating irrational beliefs takes a great deal of time. Some of these ideas have been held by our society for many years, handed down from generation to generation, and even presented as the *ideal* in advertisements. As briefly illustrated below, the Healthy Beginnings Program places a strong emphasis on the deliberate use of logic, the development of more flexible and appropriate expectations, and the introduction of specific behavior patterns.

1. "I *should* be able to detect and meet all of my child's needs." Babies are complex. They have a multitude of needs and desires and only a few ways of expressing themselves. A cry can mean "I'm hungry," or "My diaper needs changing," as well as "I want company." This is a strange new language which takes time for parents to understand. Infants have another form of communication which is often overlooked: body language. The needs of an individual infant are often most effectively determined by observing bodily reactions. The pace of play activities and routines should initially be set by the baby with new play objects, people, places, or games introduced only gradually. Due to their immature nervous systems, premature

babies generally require a longer time than full-term infants to adjust to changes around them. It is crucial to observe body signals so that an activity does not become overstimulating or frustrating. Time spans of one or two minutes are often the limit of a premature infant's ability to work and concentrate on learning something new. Over time, and with careful observing, the parent-premature infant routines will be able to blend almost as well as that of a parent-term infant couple.

2. "I *should* be a competent parent at all times; being frustrated and complaining are not acceptable behaviors." Raising any infant, most especially one born prematurely, is difficult. It is normal to be tired and frustrated. If parents were not tired, this apparently unlimited source of energy would be of great interest to scientists the world over! Every parent gets tired and complains—sometimes. However, parents of prematures have far more impositions on their time, energy, and emotions. Research and direct experience is showing that the levels of stress for these parents are exceedingly high, even when compared with parents of term infants. Thus, parents of prematures are in dire need of emotional and physical support as well as stress management techniques.

3. "I *should* be in complete emotional and intellectual control at all times." Emotions can often be so intense that they are overwhelming; even good feelings can be breathtaking. The experience of intense emotions and how each person responds is unique. People who tend to be "thinkers" use logic and their intelligence to analyze and respond to emotions. People who are "feelers" often get wrapped up in the emotional experience and do not immediately look for solutions. When a feeler and a thinker are in the same emotional storm, their philosophies and behavior patterns create extra pressure. Neither can understand the other's style of coping and both feel misunderstood and abandoned.

Although most new parents experience temporary relationship quarrels due to stress, the parents of a premature experience even greater relationship stress. They continually rely upon each other for support during the many months of the infant's hospitalization. In some cases, the differences in a relationship, when magnified over a long period of time, can bring what was a previously healthy relationship to a serious breaking point. It is vital that parents acknowledge, understand, and support the differences in styles and are willing to make compromises with each other.

4. "I *should* constantly work with my child at home to overcome the impact(s) of a premature birth." Developmental delays in prematurely born infants are well-documented and, typically, most parents are told about them while their baby is in the NICU and before he or she is discharged home. Overly eager parents of prematures, in their concern for the remediation and prevention of delays in development, frequently attempt to hasten the process by "working" with their infant at home as often as possible, as many hours as the infant and schedules will allow. However, this tremendous amount of time and effort may be best directed into mutually enjoyable activities.

The precise amount of "play" needed and accepted by each baby will vary. The infant's unique rhythm and periods of alertness should be used as times to introduce new activities, exercises, positions, and games. Bodily responses should be monitored and activities stopped when the baby loses interest or shows signs of being over-stimulated. These activities can be done many times during the day, each time for only a few minutes. If occasions to "work" are rigidly scheduled, both parent and baby will soon view the activity as drudgery and something to tolerate and hurry through. In most cases, therapeutic recommendations can easily be made into fun by the use of attractive toys, music, rhyming songs, and the adoption of a positive, playful attitude. "Working" thus becomes "playing" and a time for enjoying each other.

5. "I *should* enjoy caring for my child's needs and want to be with him/her as much as possible." In daily life, adults do many things which are necessary but not enjoyable. Taking out the garbage, paying taxes, returning phone calls, cleaning ovens, and sitting in traffic are just a few examples. These routine activities are rarely a source of compliments and pride. The same ideas apply to parenting. Not many parents change diapers with great zeal and enjoyment, but the diapers are changed whenever necessary. No baby will say, "Thank you for changing me so quickly. I feel much better now." With any luck, a smile and coo is received in return. It is unrealistic for any parent to expect to enjoy all aspects of baby care or being with an irritable, demanding, or inconsolable baby. Parents of prematures often feel guilty or criticize their parenting abilities when they find themselves irritated or frustrated by particular aspects of baby care or the infant's temperament. In part, the guilt is aroused by recalling the many months of hospitalization, anxi-

ety, and their intense hopes that the infant will be well and able to go home. Now that this fragile, long-awaited baby is home, they expect to enjoy being together. However, the reality of being home with an irritable or unpredictable infant can certainly make it difficult to fulfill such an irrational expectation.

6. "I *should* unquestioningly rely upon and allow medical personnel to direct my child's care; they are the authority on my child." It is important that parents understand how decisions are made and what the long- and short-term goals are for their child. Once parents know why particular behaviors or skills are important, they are able to handle most decision-making situations at home and even create their own strategies for promoting growth. Parents of prematures have to master very large amounts of information regarding their babies. At times, the diagnoses and treatment recommendations for a premature infant are overwhelming, lengthy, complex, and often are not definite. Mothers and fathers have endless concerns regarding the development of a child as well as their own parenting strategies. Many of these concerns seem trivial to an outsider, yet plague the parents. Often these concerns can be eased with a bit of information or reassurance once the parent asks questions. It is most critical for parents of prematures to try to overcome or temporarily put aside their fear of receiving "bad news"—the fear that makes them reluctant to ask questions. Information can empower parents in their efforts to provide the best environment for promoting the healthy development of their infant.

7. "I *should* be able to follow through on all therapeutic recommendations to improve my child's progress." Sooner or later the parent of a premature infant is the recipient of many suggestions and recommendations for activities designed to enhance the child's developmental progress. It is also likely that many of these activities will overlap or be available from only one or two individuals or through a specialized clinic or center. Parents may want to implement some suggestions at home, combining a home program with follow-up visits to specialists. Therapeutic services cannot be totally beneficial if they create great amounts of stress in other areas of family life. The ultimate task, and possibly the most difficult for a parent of a premature, is to organize a large amount of information from diverse specialists and prioritize the child's needs, keeping in mind the family's realistic ability to provide the services.

8. "My child's development *should* be similar to other children's and those in books on normal development." As parents of premature infants follow their baby's development, it is important for them to keep in mind that infants grow at various speeds and reach milestones in different sequences. Books on child development naturally presuppose normal delivery dates. The premature infant does not spend the entire pregnancy in the womb; the growing that is done in the premature's first few months *after* birth is similar to the growing done by the term fetus *prior* to delivery. To expect a premature infant to achieve milestones and physical growth in accordance with the birth date does a disservice to the infant and to anxious parents and relatives; he or she is simply not ready! When monitoring development, parents of prematures should consider the infant's corrected age in order to take into account the extent of the infant's prematurity. Developmental progress in the premature child is often compared to what would be expected from a full-term child who was born near the premature's expected date of delivery. Corrected age should also be used when comparing the premature's development with that of other children or when using books on "normal" child development. This simple procedure will be quite effective in reducing the number of irrational and inappropriate expectations related to the infant's progress.

9. "My intimate and social relationships *should* be of lesser importance than being with my child." For all practical purposes, a baby is totally dependent upon adults for many years. Parents are his or her security. It is important to remember that one parental mission is to create a warm, nurturing, accepting home for the child. The location, building structure, and family members living in this home are not very important. The love, support, consideration, and concern for others is truly what "makes a house a home" and gives a child strength of spirit and high self-esteem. Nurturance, support, and positive attention enhance support systems and intimate relationships that will create a positive environment for the new family. These relationships are, therefore, just as important as the parent-child relationship.

Family and individual behavior patterns and habits are resistant and slow to adapt to changes. Unexpected twists in routines create a great deal of stress and unbalance. Steadiness returns once new rules, behaviors, and relationships are defined. The premature birth of a child and all of the associated medical crises are unexpected and upset the family's balance. Family and support systems are ill-prepared

to deal with this vast amount of stress and fear. Most relationships survive, but they are battle weary. It is vital to the long-term survival of a family that a constant level of energy is put into rebuilding and nurturing intimate and social relationships. However, the schedules and demands of caring for a prematurely born infant do not contain much, if any, free time. These parents must work hard to carve out small pieces of time for each other by planning and scheduling intimacy around and despite the baby's schedules.

10. "Everyone (spouse, relatives, friends, co-workers, medical staff) *should* realize how hard it is to be a parent of a premature infant and they *should* show their respect and gratitude." People cannot share identical experiences. Friends, family, and professionals may have an idea about a parent's daily struggles, but these notions are always imperfect. It is reasonable for parents to expect others to offer advice, respite, and other forms of help. However, it is irrational to expect to be admired, appreciated, or adored. Most successful parents let their reward and satisfaction for a job well-done come from inside. They go about life with calmness, efficiency, and courage which is noticed by everyone.

Families with children, and especially those with premature infants, go through tremendous upheavals and extreme physical and spiritual demands. It is not necessary for parents to assume that they must struggle alone in order to provide for and encourage an infant's development. When parents are able to develop specific questions and clearly outline their needs, the process of adjusting to home life with a prematurely born infant is smoother. Parents must choose how they cope and, ultimately, how the family functions over time.*

*For additional information on parenting premature infants or the Healthy Beginnings Program, contact: Elizabeth Sledden, Ph.D., Meyer Center for Developmental Pediatrics, 8080 N. Stadium Drive, Suite 2300, Houston, Texas 77054.

Charlie's first birthday was rapidly approaching. It hardly seemed that a year had passed since Jan and Matt rushed to the hospital and Charlie was born, looking like a wrinkled old man. Money had gotten even tighter and Jan missed adult companionship and her work. Jan had returned to work after Charlie had been home three and a half months. After a long search, they found a woman who cared for a small number of babies in her home who would take care of Charlie during the day. It wasn't his home, but Charlie seemed to enjoy being there with the other children. Jan dropped him off in the morning and Matt picked him up on his way home from work. Their evenings passed quickly, consumed by feeding, bathing, and reading to Charlie. Once he began sleeping through the night, both Jan and Matt had more energy in general, and they began to enjoy each other again. The time between Charlie's bedtime and their own quickly developed its own routine. Matt would read the paper and go through the mail. Jan would clean up the kitchen, turn on the television, or read a magazine. It was too good

to be true! There were always chores to do, the piles of laundry and dishes were always there. After many different schemes for dividing responsibilities, they found that by helping each other, the chores were done more quickly and there was more time to relax and be with each other. Matt and Jan were partners in taking care of Charlie and their home.

Charlie's health had improved a great deal. His eyesight and hearing were normal. It had been a long time since he was on oxygen or an apnea monitor at home. There was still the fear of pneumonia and going back to the hospital. That had happened in the winter, when Charlie caught a cold at a holiday party. He only stayed at the hospital for two days that time. But while he was there, Jan felt the old worries come back; the little voices that said he might not get well. Jan was determined not to let Charlie get sick again. She screened visitors and their children for colds or signs of the flu. Nevertheless, she or Matt sometimes caught a cold and then so did Charlie. They survived reactions to immunizations, ear infections, sore throats, congestion, croup, diarrhea, and constipation.

The biggest struggle continued to be weight gain and feeding. As Charlie grew, he was able to try finger foods. He preferred to play with the spoon and food, rather than eat it. Many calls were made to the pediatrician about feeding, and numerous discussions took place with other parents and the professionals at the Healthy Beginnings Parent Education meetings. The advice was that no matter how little it seemed he was eating, Charlie would eat when he was hungry. This information didn't ease Jan's mind. It was such a turnaround from the hospital days when an ounce made all the difference in how "healthy" Charlie was. Now the loss of a few ounces was no big deal? It was very hard for Jan to change her attitude. She still worried about every aspect of Charlie's life. It was a habit by now. Matt helped break her pattern by taking Charlie new places and allowing him to crawl around and explore. Jan watched from afar, nervously, but proud. Jan was the hesitant one, afraid of what Charlie would put into his mouth or crawl on. Matt insisted it would be okay, and, to her surprise, it usually was.

Charlie began showing that he had his own ideas. Some were excellent; he was learning how to drink from a cup. Others were not so good—such as trying to put things in his ears, pulling on electrical cords to help him stand up, and chewing on rocks. Jan and Matt began to make compromises and set limits. They were surprised when professionals at the Meyer Center began to discuss discipline

strategies with them. Other parents spent time at the evening meetings discussing how they were trying to teach their babies limits. But Charlie seemed too young to understand rules and discipline. A firm "No!" always caught his attention, but not for long. Charlie tried to reach forbidden things over and over again. The best strategy was to remove him from the tempting situation. Sometimes giving him distractions didn't work, and he screamed and screamed. It was often easier to give in than persist in setting rules. Was this what people meant by the "terrible two's?" Charlie was barely one year old! Jan and Matt's mothers said it was a sign of curiosity and marveled at how bright he was. They didn't have to watch his every move!

The family's life was settling into a comfortable routine. Sure, they worried. What parent doesn't? Jan found her worries were slowly becoming similar to those of her friends who had term babies. Success seemed a long way away. The future for a premature is often unclear. Matt said they would deal with things as they happened. After all, they had weathered more in a year than most parents do over a lifetime! It was true; life was starting to seem "normal." They had spent the past year longing for things to be "normal." Was this it? It wasn't what they had expected life with a child to be like, but it felt comfortable and somewhat predictable. Their life now was light years away from their life before Charlie. But was that life before Charlie "normal?" It might have been, for couples without children. Maybe what the books and movies call "normal" is no more than one person's idea. Maybe normal is whatever one gets used to doing and feeling. Maybe, just maybe, "normal" is nothing more than a positive, confident state of mind.